HCFA MARKET RESEARCH FOR BENEFICIARIES

THIRD INVENTORY REPORT VOLUME I

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CHAPTER 1

INTRODUCTION

HCFA Market Research for Beneficiaries

As part of its strategic plan, the Health Care Financing Administration (HCFA) has undertaken an Agency-wide initiative to adapt its operations and communication strategies to better serve its customers and partners. A goal of this initiative is for HCFA to improve communications with Medicare beneficiaries. By providing information about Medicare in formats that are easily understandable, HCFA can assist beneficiaries in making appropriate choices among healthcare delivery systems, providers, and treatment options, and in using the Medicare program effectively.

Because HCFA is responsible for assuring healthcare security for all customer groups, information on Medicare that is tailored to the needs of beneficiaries can help to achieve this objective. To that end, HCFA has identified a diverse set of beneficiary sub-populations that it believes may have special information needs regarding the Medicare program. In this Inventory Report we included beneficiaries who (1) have difficulty seeing, (2) have difficulty hearing, and/or (3) either have a low education or literacy level. Other Inventory Reports discuss the needs of both the general Medicare population and other selected sub-populations; such as, African Americans, Hispanic Americans, dual eligibles, rural beneficiaries, and people who are about to enroll in Medicare.

Profile of Populations

The three sub-groups for the Third Inventory Report comprise a significant portion of the Medicare population.

VISION

- **1** in **6** individuals over age **65** have lost some vision
- **1** in **4** individuals over age **85** have lost some vision

HEARING

- **1 in 3** people over age **65** have some degree of hearing loss
- by age **85**, this number increases to **1 in 2**

LOW EDUCATION

- **2** of **5** older adults read below the fifth grade level
- **3** of **5** older adults have limited reading and comprehension skills,

Following is a synthesis of our findings on beneficiary information needs, the processes used by organizations to understand those needs, and the "best practices" for communicating information on Medicare and staying healthy to seniors whose physical and cognitive needs may require specialized methods of communication. Some of the Third Inventory findings apply to all three of the groups considered in this report, whereas other findings are particularly relevant to the specific groups.

The following two questions are the focus of the market research:

- **What information do beneficiaries want and need from HCFA?**
- **How can that information be most effectively made available?**

As part of our effort to determine the information needs and the communication strategies of the visually and hearing impaired, as well as low literacy beneficiaries, we conducted interviews with different organizations that work with the identified groups. The goal of contacts with these entities was to learn both about the characteristics of effective and ineffective communication strategies with Medicare beneficiaries from the groups, as well as about additional organizations we could potentially interview. Our list includes local and national advocacy organizations, social service agencies, and providers. Telephone interviews were conducted, with site visits to those organizations in and around Washington DC. The table below contains a list of organizations and their geographic location interviewed for the inventory organized by type.

Organizations and Individuals Interviewed for the Third HCFA Market Research Inventory

National Organizations	Location
The Lighthouse National Center for the Blind	New York, NY
The National Council on Aging	Washington DC
National Work Group on Cancer and Literacy	Denver, CO
National Institute for Literacy - Breast Cancer Oral History Action Project	Berkeley, CA
American Optometric Association	St. Louis, MO
Advocacy Organizations	
American Council for the Blind	Washington, DC
Council of Citizens with Low Vision	Kalamazoo, MI
The Center for Independence, Technology and Education for the Blind and Visually Impaired (CITE)	Leesburg, Florida
National Association of the Visually Handicapped	New York, NY
National Federation of the Blind	Baltimore, MD
Better Hearing Institute	Alexandria, VA

Advocacy Organizations continued	
Self Help for the Hard of Hearing, Inc.	Bethesda, MD
Communication Services for the Deaf and Hard of Hearing	Greensboro, NC
Hard of Hearing Advocates	Framington, MA
League for the Hard of Hearing	New York, NY
Literacy Research Organizations or Agencies	
Institute for the Study of Adult Literacy	University Park, PA
Ripkin Learning Center	Baltimore, MD
American Literacy Council	New York, NY
Operation Bootstrap	Lawrence, MA
Prudential Center for Health Care Research	Atlanta, GA
Literacy Council of Northern Virginia	Falls Church, VA
Health Literacy Center, Maine Area Health Education Center	Biddeford, ME
Government Agencies	
District of Columbia Office on Aging	Washington DC
Service Providers	
InTouch Radio Network	New York, NY
TryNet	Nutley, NJ
Deaf Services Program, Baltimore Medical System	Baltimore, MD
Medicare Carriers	
Blue Cross and Blue Shield of Florida	Jacksonville, FL

What did we learn from the Market Research?

The Market Research for Beneficiaries project uses information gathered from several sources. This Third Inventory Report contains findings from a review of the literature and interviews with over 25 organizations providing services directly to these groups. Several issues and themes emerged from our research:

- Each group represents a larger number of seniors than is commonly thought. For example, while only 0.8 percent of beneficiaries are totally blind, 7.15 percent of beneficiaries suffer from visual impairment which can not be corrected. Approximately 25 percent of beneficiaries suffer from an eye disease which may adversely affect their everyday functioning;
- Each group experiences barriers to being able to access information in traditional formats, whether the barriers be physical (such as not being able to physically see a document to read it or hear a telephone operator's answer to a question) or cognitive (not being able to understand the materials or message);
- Each group has developed compensatory abilities, such as an acute sensitivity to the spoken word or other people's body language, that can facilitate HCFA's efforts to provide them with information;
- Although HCFA is the major insurer of people with disabilities, hearing and visually impaired beneficiaries do not tend to think of the Agency as a source of information;
- Not being able to read, or see or hear is an "invisible" barrier to communication in that it is not obvious to an observer. Individuals often feel

ashamed of the impairment and try to hide it; and,

- A disproportionate number of the more severely impaired members of each of these groups are among the lowest socioeconomic strata.

To a greater or lesser extent, these six findings pertain to all three groups; vision and/or hearing impaired, as well as low literacy individuals. In addition, each group has specific needs for information, which are described later in this report.

The findings of this Inventory have three main implications for HCFA:

1. Like the general population, these three groups of beneficiaries have significant needs for a range of information on the Medicare program, not just information specific to their disabilities. However, simply providing more information is not always the best approach. Information needs to be layered in its presentation and pre-digested, because individuals in these groups often lack an organizing framework for it. In some cases, providing less information can be a more effective approach;
2. Traditional dissemination vehicles, such as printed materials or toll-free telephone numbers, must be adapted or expanded in order to more effectively communicate information to these groups. For example, because it is difficult to identify who is low literacy, print materials might be adapted in format to include graphics and simple summary statements of the accompanying text in the margins, so as to address both the senior who has difficulty reading (and who can get the whole story through the summary statements) and the senior who wants to see all the detail (who will probably view the summary statements as an outline). Toll-free telephone reading service (of *Your Medicare Handbook*, for example) can be offered for the visually impaired who can listen to either a live or computerized "reader" and navigate through the document using the keys of the telephone; and
3. HCFA will need to decide upon the role it wants to play in providing information on services not covered by Medicare. For example, most assistive devices and rehabilitative services for vision or hearing impairments are not covered by Medicare, yet these are areas in which beneficiaries have significant information needs. The Agency must decide whether to limit its participation to services covered by Medicare, for example, or whether it wishes to more broadly serve beneficiaries, such as being a clearinghouse for information on specific services.

CHAPTER 2

BLIND AND LOW VISION

Behind arthritis and hearing loss, reduced ability to see is the most prevalent health condition among the elderly population. Since HCFA relies extensively on printed materials to disseminate information on Medicare and staying healthy, the visually impaired may not be effectively served. Understanding vision impairment and its impact on individuals' communication capabilities is essential for the Agency.

Aids that are commonly used by low vision individuals include:[1]

- eyeglasses,
- contact lenses,
- hand held magnifiers,
- face worn magnifiers, and
- closed circuit televisions (CCTVs).

What do blind and low vision beneficiaries need to know about Medicare?

The information needs of the low vision and blind populations regarding the Medicare program are similar to the needs of the overall Medicare population. Customarily, beneficiaries need information about the services Medicare covers, how to find providers, costs, and managed care options. Medicare does not usually cover eyeglasses and assistive devices. Therefore, HCFA is not viewed as a primary source of information on these important health services. Because HCFA seeks to provide beneficiary centered information about staying healthy to seniors, HCFA may want to provide beneficiaries with information about these services, or it may want to inform beneficiaries on how to find this information.

Common Medicare Questions Asked by Visually Impaired Beneficiaries:

1. "What *services* are covered under Medicare? Are glasses, CCTV's and other necessary *low vision tools* covered by Medicare?
2. "Who *pays* for low vision services? Are services covered by Medicaid?"
3. "What is the role of *managed care* in Medicare? How does managed care fit into the health insurance system? Why do some plans offer to cover eyeglasses while Medicare does not?"
4. "Who do I contact for Medicare information?"

[1] There are other available tools for the low vision population, but the list above consists of the more common and widely available devices.

Individuals with vision impairments typically ask questions about the availability of low vision aids and services, as well as general eye health maintenance and how it is related to their health insurance coverage. These questions are commonly directed to organizations working in the visually impaired community that deliver various social services.

One very important consideration is that nearly three quarters of the visually impaired population has been unemployed throughout their lives, many of whom are very poor. Because paying for assistive devices or even basic health care is difficult, many questions asked by visually impaired individuals are related to insurance coverage and financing for their health care and vision needs.

What are the health information needs of blind and low vision beneficiaries?

The health information that visually impaired individuals most often need is related to eye health: the treatment of related eye diseases, as well as the loss of sight.

Remaining Independent. A major issue for the visually impaired is to be able to function independently, or to regain independence after they have lost some or all of their sight. Optometrists and eye care providers are often able to help individuals live more independently through low vision rehabilitation. Low vision rehabilitation consists of training in skills that enable people to perform the activities of daily life in a variety of new ways. In addition, individuals are trained in how to make use of available tools for the visually impaired. An example is training in mobility, where the person learns how to travel in new ways. These ways include using a cane and making better use of peripheral vision. Unfortunately, it is estimated that only **25 percent** of individuals affected by low vision actually take advantage of low vision rehabilitation, either because they are unaware of its availability or because they are not able to afford the service. Information is needed on available services that can help individuals maintain or regain their independence.

Eye Health. For a variety of reasons, individuals lose visual ability as they age. This is due to both age-related structural changes in the eye and the loss of sight from eye diseases.

- *Age - Related Structural Changes.* As individuals age, structural changes in the eye take place, such as thickening and increased rigidity of the lens, the lens growing more opaque, deterioration of the retina, and changes to the iris and the pupil. These changes all contribute to reduced acuity, increased or the development of far sightedness, decreased color determination and depth perception, increased sensitivity to glare, and a decreased ability to adapt to light and dark.

Percent of Beneficiaries with Eye Diseases by Age

- *Eye Diseases*. There are four main "culprits" that rob elderly individuals of their vision; (1) macular degeneration, (2) glaucoma, (3) cataracts, and (4) diabetic retinopathy. Each is progressive and more likely to occur as one ages. Approximately 25 percent of individuals 65 years and older suffer from one of these diseases. By the time individuals reach age 75, one in three persons has one of these four eye diseases. All but one of these diseases, macular degeneration, are linked to diabetes. (Ten percent of seniors currently have diabetes.) Providing information to Medicare beneficiaries about diabetes and eye diseases may help them to participate in screenings and seek timely treatment, thus reducing the chance of losing their sight entirely.

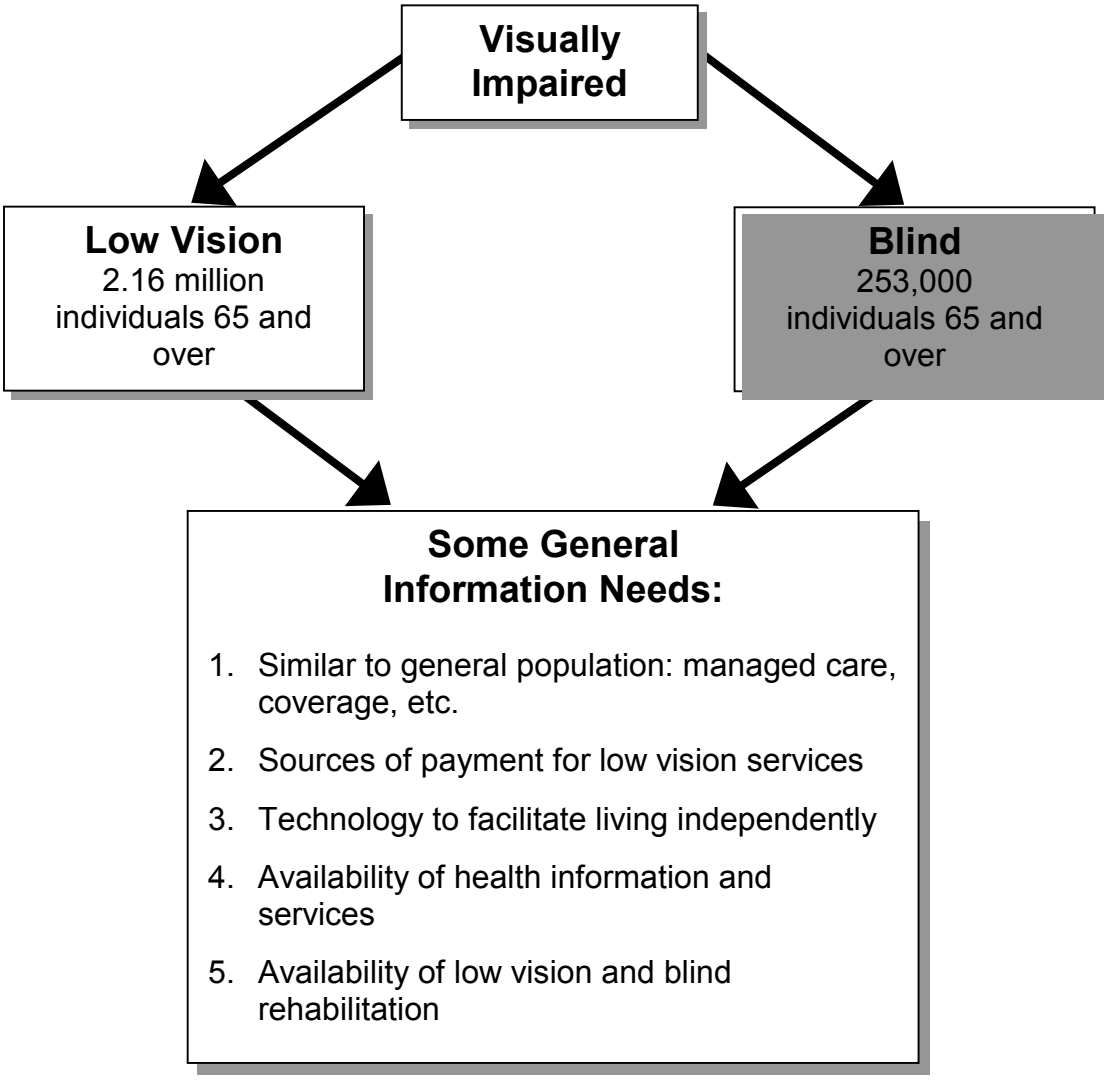
The "visually impaired" includes both individuals with low vision and those who

Ages	Cataracts	Glaucoma	Diseases of Retina[2]
All Ages	2.58%	0.98%	0.52%
55-64	3.80%	1.80%	0.61%
65 and older	16.43%	5.29%	2.75%
75 and older	22.89%	6.76%	4.09%

are blind. The low vision group is approximately ten times the size of the blind. While the information needs of low vision and blind beneficiaries differ, there are some similarities. The following figure highlights the information needs that both groups share.

[2] Diseases of the retina includes both diabetic retinopathy and macular degeneration.

Shared Information Needs



What strategies do organizations use to communicate and disseminate information to the blind and low vision communities?

The blind and visually impaired communities are different. The low vision population usually has some residual sight, and is able to make use of different communication methods and tools than the blind. Because both blind and low vision individuals are more reliant on their other senses, usually hearing, to compensate for a decreased ability to see, there is some crossover in the strategies and tools that may be used.

Generally the communication strategies for the blind and low vision beneficiaries are similar, but the specific applications used for the groups differ.

THE NEEDS OF BLIND AND LOW VISION ARE DIFFERENT

Communication Activities	Blind	Low Vision
Distribution of Materials	Narrowly targeted -- small population of approximately 253,000 individuals 65 and over	Widest possible - larger population approximately 2.165 million individuals 65 and over
Partner With Local Organizations	Relatively well developed network on place for the blind -- social service organizations and advocacy groups	Need to develop a network - organizations solely providing services for the low vision community are few in numbers
Use Multiple Modalities	Braille, audio cassette tape, computers with speech capabilities, CD-ROM products, radio	Print materials, audio cassette, computers with speech capabilities, video with print materials, ratio, Internet
Use Existing Services Provided by Organizations	May include, rehabilitation and independent living, counseling, health promotion and mobility training	General services to the elderly--senior centers, AARP, (there are few organizations serving strictly the low vision community)
Develop or Expand Technologies(e.g. Telephone system, computer systems, Internet)	Develop a telephone system for access to *Your Medicare Handbook,* being read live or by computer	Develop computer discs to be used with computer readers or voice synthesizers
Adapt Existing Materials (e.g. *Your Medicare Handbook*) **	Convert print materials to Braille or audio cassette	Use large font, simple backgrounds, concise contrast, matte paper, well defined text flow Convert radio to audio cassette

***Please note:* Materials that are in a larger print and formatted for the low vision, can be read by individuals with some residual sight on a closed circuit television (CCTV). This is a tool for low vision persons that magnifies the text for the electronically onto a monitor screen. Other tools such as magnifiers or electronic equipment that reads the materials can be used by low vision individuals to help read text.

Which tools or vehicles do organizations and individuals use to facilitate communication with the blind and low vision populations?

Because blind individuals have very little to no residual vision, tools are adapted to utilize the individuals' other sensory strengths, rather than relying on vision. Tools that have been developed for the blind are catered to their compensatory strengths, such as touch and hearing. Individuals who become blind late in life will not have developed the skills to use some of these tools, however, such as Braille. The following are examples of tools or vehicles commonly available to blind beneficiaries:

- 1-800 numbers;
- Braille;
- Audio cassette and tape recorders;
- Computer discs to be used with speech synthesizers or computer readers; and,
- Radio reading services.

On the other hand, individuals with low vision are usually able to rely on some residual vision that allows them to make use of additional communication vehicles, including print materials. Because their vision is limited, however, tools should also be adapted to allow the individual to use their other compensatory senses, such as hearing. The following are examples of tools or vehicles used by low vision individuals:

- 1-800 numbers;
- Audio cassette and tape recorders;
- Broadcast radio;
- Videos with read-along materials;
- Internet; and,
- Computer discs to be used with speech synthesizers.

Recommendations for Adapting Print Materials:

For reaching the low vision population, we heard one particular recommendation throughout most of the interviews. **Adapt written materials** for persons with some residual sight. Informants suggested the following adaptations:

Larger font should be used when creating text. Font size should be increased to at least twelve point. For those with visual impairments, a font size of fourteen to eighteen is recommended.

Good contrast is important so that better distinctions can be made between letters and words. The best contrast is created with black text on white paper.

Quality paper is also highly recommended for printed text. Paper with gloss creates glare; paper that is too thin allows print to bleed through from the other side, which also decreases the readability of the text. Paper should be thick with a matte finish, and be of sufficient weight.

Use of Columns and Well Defined text flow aid in an individual's seeing where text begins and then continues. If columns are used in the text, a break line between columns aids a visually impaired reader to more easily follow the flow of text Indenting paragraphs also better defines the text flow, which, in turn increases the readability.

Logical text is also highly recommended for the visually impaired. Avoid using references to items on other pages or in appendices. It is more difficult for the visually impaired to flip back and forth between pages in the text to appendices and references.

Computer screens should be an amber color for the visually impaired. Blue and green backgrounds should be avoided, because characters are more difficult to distinguish against these colors. Most graphics on computer programs and on Websites are difficult for the visually impaired to discern. Respondents noted that they are usually too cluttered. It is recommended to keep graphics and backgrounds *simple* because it is easier for a visually impaired person.

Summary

- Blind and low vision persons represent a substantial portion of Medicare beneficiaries;
- These groups need a range of information on the Medicare program, as well as information related to their impairments;
- More information is not necessarily better;
- HCFA needs to determine the role it is going to play in information dissemination to these beneficiaries about services not covered under Medicare. In the meantime, the Agency can adapt existing products to better serve those with visual impairments:
  - adapt written materials for low vision readability;
  - create telephone access and audio cassette versions of *Your Medicare Handbook*. This allows the beneficiary to use the telephone key pad and the audio cassette recorder to move around the recording;
  - Internet information that can be adapted to use with speech synthesizers; and,
  - local or community intermediaries can be enlisted to help facilitate the dissemination of information.

CHAPTER 3

DEAF AND HARD OF HEARING BENEFICIARIES

Individuals who have hearing loss represent a large group of beneficiaries with a broad range of hearing and linguistic capabilities. Capabilities can range from mild loss of only certain frequencies to total deafness. Consequently, these individuals face obstacles when attempting to access and understand information presented in a format designed for a primarily hearing population. At one end of the spectrum, individuals with mild hearing loss are able to participate in oral conversations with little difficulty, but may require repetition of phrases or words if the sound source is not directly in front of them or if there is competing background noise. Further complicating communication for these beneficiaries is the psychological dimension of hearing loss. The negative social stigma associated with hearing loss and the widespread denial often lead individuals to isolate themselves and withdraw socially, making outreach and general communication very difficult.

Profoundly deaf individuals comprise the other end of the spectrum of hearing impaired. For these individuals, their primary form of communication is visual, such as through American Sign Language (ASL) or print materials. Unlike those who have lost hearing in later years, early on-set deaf individuals are likely to have developed effective personal communication channels and tools which either allow them to access information or call upon a resource to interpret or access the information for them. Recognizing the diverse and differing needs of the hard of hearing Medicare beneficiaries is therefore crucial for HCFA as the Agency develops a comprehensive communication strategy to ensure that all beneficiaries are well informed of their Medicare coverage, options and consumer rights.

What do deaf and hard of hearing beneficiaries need to know about Medicare?

Hard of hearing and deaf beneficiaries ask many of the same questions and demonstrate the same gaps in understanding about Medicare as the general population. Furthermore, the questions that hearing impaired beneficiaries ask about Medicare are not necessarily related to their level of impairment. Although all of the organizations interviewed make a clear distinction between the general communication strategies for reaching deaf and hard of hearing individuals, the information needs of both groups on health insurance and Medicare are similar.

There is general confusion over the services Medicare does and does not cover, the concept of a physician "accepting assignment" and general administrative questions over claims payment and who to contact for appeals or claims status. Beneficiaries struggle with basic Medicare concepts such as "out-of pocket expenses", and often do not understand the distinction between the Social Security Administration and HCFA, or between the carrier and their personal insurance companies.

Managed care is an increasingly confusing and frustrating topic, in terms of its relationship to Medicare and the coverage arrangement under managed care. Because Medicare does not provide coverage for hearing aids or assistive listening devices, hearing impaired beneficiaries tend not to think of HCFA as a resource for Medicare or managed care information, and do not understand why some managed care plans offer hearing aids while Medicare does not.

Common Medicare Questions Asked by Hearing Impaired Beneficiaries:

1. What is assignment?
2. How do I choose a doctor?
3. Why can some doctors charge more then Medicare allows?
4. Does Medicare cover my hearing aids?
5. Will I have to pay more for managed care?
6. Does managed care cover hearing aids?
7. What does "in" and "out of network" mean?
8. What is a co-payment and an out-of-pocket expense?
9. What are assistive listening devices and does Medicare cover them?
10. Who do I contact for Medicare information?

What are the health information needs of deaf and hard of hearing beneficiaries?

Given the diversity in both beneficiary functioning and the types of services available, both formal and informal, it is difficult to rank order the information needs of hearing impaired beneficiaries. A common desire among deaf beneficiaries is to be able to access and understand information, even to frequent a clinic or organization that serves hearing impaired clients in order to facilitate this process.

Deaf beneficiaries are considerably more likely to have established channels for receiving information and often can depend on sign language, for example, as a reliable form of communication. Individuals who have lost their hearing in later life no longer have a dependable method of communication and are likely to be uninformed about both their hearing loss and the utility of seeking medical and mental health help.

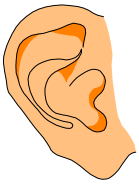
Information needs, beyond the Medicare and managed care issues discussed above, focus primarily on the impairment itself, including treatment, diagnosis,

alternative communication tools, "key" hearing healthcare providers (e.g. otolaryngologist, audiologist), assistive technology and coping strategies. These needs differ according to the extent of the individual's hearing loss, the coping strategy used, as well as the extent to which he/she is in denial of the loss of functioning. Interview respondents reported that hard of hearing beneficiaries are primarily concerned with the following:

Cost/Reimbursement --A major concern for hard of hearing beneficiaries is being able to afford hearing aids, screenings and associated tests, most of which are not covered under Medicare. There are organizations, such as Hear Now, that can offer financial help and planning.

Coping strategies -- Many people with a hearing loss accept it is a part of growing older and feel that nothing can be done about it. "Normalizing" hearing loss counteracts the denial and increases the likelihood that the individual will seek help and information.

Hearing/Ear health -- Because hearing loss is often not considered a critical health issue compared with other conditions associated with aging, such as cardiovascular disease, beneficiaries and their physicians do relatively little to maintain proper ear health or to explore the various treatment options for hearing loss.



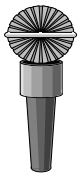
Seniors need to know that they should maintain ear health.

Hearing specialists and doctors -- Who's who in the medical world of audiology, such as the otolaryngologist.

Consumer Fraud -- This is particularly important for older people with hearing loss who are more vulnerable and susceptible to aggressive vendors. Information on how to evaluate hearing aids and vendors, consumer rights, and how to file a complaint are important to these beneficiaries.

Telecoil (T-switch) awareness -- The telecoil is an option available with hearing aids which allows the user to couple with assistive listening systems and telephones. Individuals shopping for a hearing aid are generally unaware of the benefits of a telecoil, or that it even exists. The telecoil is a relatively inexpensive option, but only if it is inserted at the time of purchase. Retroactively fitting a hearing aid for a telecoil can be expensive and difficult.

Assistive Listening Devices -- Assistive listening devices (ALDs) are technological devices which can improve face-to-face communication and facilitate the use and enjoyment of television, radio and the telephone. One class of these devices, the soundbridge, helps the user focus on desired noises or sound sources by targeting the structures of the middle ear. Soundbridges combine both externally worn and surgically implanted components to reduce distortion and feedback and increase the signal to



ALD's often use microphones to amplify sound.

noise ratio. Other ALDs, such as telephone amplifiers and alerting systems, can help those with residual hearing to take advantage of environmental sounds and noises and fill the communication gaps created by hearing loss.

What strategies do organizations use to communicate and disseminate information to the deaf and hard of hearing communities?

The greatest barrier deaf beneficiaries face when attempting to access information is the absence of accessible and understandable formats. Because many deaf individuals do not read beyond the fourth grade level, many important documents and printed materials are not useful. The primary consideration when disseminating information to the deaf is to provide it in sign language through established channels within the deaf community. Organizations and agencies developing or refining a communication strategy to reach the deaf population should consider the following:

Targeted approach -- Deaf beneficiaries are likely to have well-established communication networks and information channels. The deaf community is small and close knit, making a broad approach unnecessary.

Key or prominent deaf community members as messengers -- Given the strength of the deaf community and deaf culture, working through known and respected leaders within the community will increase the credibility and reception of the presented information.

Partnerships -- Because most groups serve a broad constituency, it is difficult to develop specialized services and outreach without help and/or guidance from them. Partnerships with social and direct service groups within the deaf community who have experience working with deaf beneficiaries is an effective way to share information and enhance services.

Build community partnerships

Inside-out Guidance -- Because deaf culture and the deaf community play a significant role in how information is received, disseminated and communicated, it is best for HCFA to work with and take guidance from the community.

Different Strategies for Hard of Hearing -- Communication strategies and tools targeting hard of hearing beneficiaries, who have some functional use of residual hearing, require somewhat different activities than strategies for reaching the deaf. Health care delivery and information dissemination is compromised in particular with the elderly hard of hearing. The denial and social isolation that characterizes the adult-onset hard of hearing population impede traditional methods of delivering information. For hard of hearing beneficiaries, strategies that rely on intergenerational and peer education are particularly effective, as they concurrently develop a support network and also convey information. In addition, as service and health delivery organizations increasingly understand how to recognize people with hearing loss, the barriers to reaching isolated and

withdrawn individuals will be reduced.

Even if information is provided in an understandable format, hard of hearing beneficiaries have often withdrawn to the point where the information does not physically reach them. Many are homebound and do not take advantage of hearing aids or assistive technology. This renders the telephone, often the only reliable entree to the individual, useless. Education and outreach to empower the individual to seek help is seen as the most significant means of opening communication channels for the individual. The following strategies are important components of effective communication with hard of hearing beneficiaries:

Aggressive outreach -- Hard of hearing beneficiaries tend to be passive in their information seeking.

Visual reliant forms of communication -- Graphs and pictorial representations of text enhance understanding of the presented materials. In addition, formatting the document to be concise with considerable white space on the page and simplified sentence structure is helpful.

"One-stop-shopping" mentality -- A major barrier for hard of hearing beneficiaries is their underdeveloped "support" network. Beneficiaries are required to navigate a confusing network of information, often through an automated telephone menu or a series of calls to unrelated organizations. This frustrates them and further deters proactive information seeking. Taking the "guesswork" out of accessing information and having one's questions answered directly is extremely important for these beneficiaries.

Broad advertisement -- Because many hard of hearing individuals are in denial of their condition, an important first step in disseminating information is overcoming this barrier through broadly advertising that hearing loss is nothing to be ashamed of. Testimonials are particularly effective in this regard. Because of the prevalence of hearing loss, broad advertisements, through mass media, can be extremely effective, especially when they use well-known celebrities or public figures.

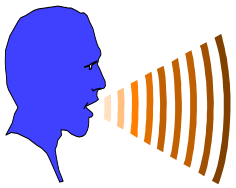
Link Information Sources with Information -- Clearly defined resources are a fundamental step in increasing access to information. Identifying which organizations, stores, groups or agencies provide what types of information is crucial to reducing duplicative efforts and increasing efficient navigation of community or national information networks.

Multi - channel dissemination -- Because hard of hearing beneficiaries do not share a common language, such as ASL, and can no longer reliably depend on the spoken word for information, dissemination through a variety of channels (e.g. television, newsprint, radio, brochures, etc.) and at a variety of locations (e.g. neighborhood banks, senior centers, doctor's offices) is important.

Identify and cross educate all "key players" in a hard of hearing individual's life

(including family members, different types of doctors, health service delivery groups, social service groups, government agencies) in order to help raise awareness of the need for developing a supportive network.

What tools do organizations and individuals use to facilitate communication to the deaf and hard of hearing populations?



Don't shout, just speak clearly!

Effective oral communication with deaf and hard of hearing people can be achieved either through enhancing personal listening ability or using alternative sources, such as visual tools. Communicate using technological enhancements to convert sound into a usable form for the individual or provide a non-audio alternative to disseminating information. It also requires investigating treatment for the individual's hearing loss, to reopen the possibility of using sound. The removal of ear wax, surgery or cochlear implants are examples of treatment options for hard of hearing or deaf persons that can restore some hearing. However, for some types or severity of hearing loss, these options are not effective and the individual must take advantage of alternative communication methods, including technological adaptations and tools.

Specific tools to facilitate communication and dialogue with deaf and hard of hearing beneficiaries are listed below. It is important to note that members of each population are not able to benefit from all of the tools. Deaf beneficiaries often do not have the residual hearing to take advantage of audio enhancing devices and hard of hearing beneficiaries do not have the signing capabilities to take advantage of ASL formats.

Communication Tools for Deaf and Hard of Hearing:

- Computerized Speech Recognition Systems - a computer software package converts spoken words into text.
- E-Mail
- FAX
- Open/Closed captioning
- Sign boxes -- Translator signs the spoken portions of the video or presentation either in a full screen format or in a box at the bottom of the screen.
- Telephone Amplification Devices
- Assistive listening devices - a variety of technologies including audio loop systems, AM/FM amplification, and infrared amplification which interact with hearing aids to amplify and clarify sound.
- Text telephones
- Text telephone/Telephone Relay Service
- Aural Rehabilitation including auditory training, speechreading, and hearing aid orientation;
- Counseling

In summary, hearing impairments affect a large number of Medicare beneficiaries. Most people are relatively uninformed about the importance of maintaining proper ear health or that treatment options exist. Although the specific information needs of deaf and hard of hearing beneficiaries are slightly different, many similar strategies can be used by HCFA to reach both groups.

CHAPTER 4

LOW EDUCATION or Literacy

Addressing the special communication needs of Medicare beneficiaries with limited education and literacy skills is important in assuring that all beneficiaries understand their eligibility, benefits, and other important aspects of a large and complex program. Medicare beneficiaries are likely to be part of the low literate segment of the population as two of five older adults read below the fifth grade level. This is twice the rate of the general US adult population. National statistics reveal that 29 million (61 percent) older adults have limited reading and comprehension skills and millions more prefer easy-to-read materials. Census data from 1990 show that while 94 percent of adults ages 25 to 64 completed eighth grade, only 24 percent of adults 65 and over completed grade eight.

Because of a lower literacy and educational attainment, individuals interpret and process information differently than more literate individuals. Illiteracy results in underdeveloped information processing skills, and many individuals are confused by complex written and verbal communication.

Characteristics of learners with low literacy skills include:

- Perception of information in bits and pieces, often without context;
- A tendency to think in concrete and immediate terms rather than abstract or futuristic circumstances;
- Literal interpretation of instructions;
- Insufficient language fluency to comprehend and apply information from written materials;
- Difficulty with information processing, such as reading a menu, interpreting a bus schedule, following medical instructions, or reading a prescription label;
- A heavy reliance on nonverbal communications;.
- Difficulty in finding and processing quantitative information in written materials;
- Limited prose skills; and,
- Difficulty interpreting and filling out documents.

Low literacy individuals rely heavily on oral explanations, visual clues and demonstration of tasks to learn, rather than on written materials. Very often, individuals have developed compensatory strengths, such as enhanced listening and memory skills, and are often very attuned to nonverbal or body language. The coping

mechanisms used by low literacy individuals can be important considerations in the

design of an effective communication strategy for HCFA.

What do low literacy beneficiaries need to know about Medicare?

Because low literacy is not a specific "health problem", most low literate beneficiaries have general health care questions rather than specific questions related to vision or hearing impairment or an associated chronic condition, such as diabetic retinopathy. Many of the information needs identified by respondents include very basic information, such as how insurance works and the basic Medicare program description.

Most of the Medicare-related questions that low literate individuals have center on the general Medicare program, as many individuals do not have enough basic information to ask more detailed or complex questions. Some of the confusion results from low literate beneficiaries relying on secondary sources of information, such as friends and family members, which may be less reliable than information provided by health care providers or HCFA. Many information needs of the low literate population center around negotiating the health care system, obtaining services, and the out-of-pocket expenses associated with Medicare benefits.

Information needs of low literacy individuals:

- Insurance and medically related terminology;
- Information related to what medical services Medicare does and does not cover and how much Medicare pays;
- Information that helps low literate beneficiaries understand out-of-pocket expenses, such as co-payments and deductibles; and,
- Fee-for-service delivery and supplemental insurance vs. managed care delivery comparisons.

What are the health information needs of low literacy individuals?

Links have been shown between literacy and educational attainment, life expectancy, infant mortality, and maternal mortality. Low literacy is considered to be a risk factor for poor physical health, as well as poor psychosocial health. Higher expenses for health care, more outpatient visits, and a greater likelihood of hospitalization have also been associated with low literate adults.

A possible explanation for the connection between low literacy and poor health is the inability to understand and/or read health related materials, such as written instructions for prescriptions and diet recommendations. Because of the lower reading level and decreased ability to comprehend complex ideas, low literate

individuals often do not comprehend basic health care directives which are important to one's overall health. To avoid misunderstanding, important medical and health related information should be written at a maximum of an eighth grade reading level, preferably at the fifth grade level.

Because of a lower level of reading ability, low literacy beneficiaries need to be comfortable with their doctors. This comfort level will allow beneficiaries to ask questions of their doctors. Low literate individuals tend to think in concrete terms and often can not understand how ideas relate to each other, which can reveal serious knowledge gaps resulting from their inability to fully understand information For example, a low literate individual will not make the connection that reducing dietary fat can mitigate heart attacks. "Dietary fat" usually has no meaning for him/her as a concept, nor can he/she understand it's relationship to cardiovascular health. Being able to ask the doctor for help or advice may alleviate some of the health risks that have been associated with the "typically" low literate individual. Asking questions of their doctors and other providers is a way to receive information that can be specifically tailored to the individual's abilities and information needs.

Health-related information that low literacy beneficiaries need include:

- Better explanations of important medical procedures, such as, how and when to take a prescribed medication;
- Clear and easy to understand instructions to describe medical directions and procedures;
- Effectively navigating the health insurance system; such as, instructions on how to fill out consent or insurance forms; and,
- Information about prevalent chronic conditions or maintaining one's health conveyed in a clear, concise, and uncomplicated manner.

What communication strategies do organizations use to disseminate information to low literacy communities?

One of the largest barriers to communicating with low literate beneficiaries is their denial and/or shame about not being able to read. It is difficult to distinguish between individuals that are able to understand written materials and those that can not. Therefore it is best to use a variety of communication methods to try to reach as many individuals as possible. For example, placing public service announcements on radio and television can reach many communities in which low literate seniors live. The key to success, however, is placing the spots on shows that beneficiaries watch, such as soap operas and game shows. Respondents noted that church-related radio shows and talk shows are also widely listened to by

seniors, and that air time on Sunday mornings is relatively inexpensive compared to primetime. It will be important for HCFA to identify the shows that are most popular with seniors, which is likely to vary with geographic area.

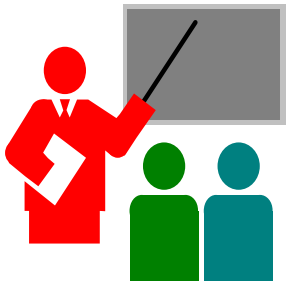
Assist seniors in understanding the Medicare program where they are, e.g., at home, churches, public libraries, grocery stores, pharmacies, or senior centers. Community senior centers provide a convenient location for seniors to gather and may be an appropriate place to convey information on the Medicare program through center staff.

Furnish ***physicians and providers*** with materials written on a lower reading level that are relevant to their patients' health care information needs. Verbal communication should precede written materials, however, because some patients may not be able to read and understand them. The written materials should serve as reinforcement for any information told to the patient verbally, and serve as a reminder later.

Provide ***intermediaries*** with a supply of materials at various levels of reading difficulty. Beneficiaries can then select a piece they feel comfortable reading. This method presents the information in a way that facilitates proactive information-seeking and can build an individual's self-esteem, rather than having damaging effects.

Literacy organizations recruit and train volunteers to tutor adults in basic reading, writing, and speaking skills, usually on a one-on-one basis. Volunteers' involvement typically exceeds reading instruction, often encompassing social work functions. For example, volunteers often help their "students" fill out complex forms, such as job applications and health insurance forms.

Literacy classrooms are an important vehicle to present health materials because: (1) health education topics are usually of interest to literacy students and may help them ultimately make better use of the health care system; and, (2) although low literacy adults find other ways to function, these compensatory measures (memory and hearing skills) may fail in older life. Thus even basic training in literacy will give seniors one more useful skill.



What specific tools do organizations and individuals use to facilitate communication with the low literate?

Low literacy individuals rely heavily on verbal explanations, visual clues and demonstrations of tasks to learn. It is possible for HCFA to approach them with communication tailored to their strengths, as well as with print materials that may be used to reinforce important health information. Individuals that are low literate usually have enhanced listening and memory skills to help compensate for their inability to read, so public service announcements carried on radio and television can be particularly effective.

Organizations often tailor their methods of communication to use low literacy individuals' compensatory skills and aids. For example, seniors often have family members who read printed materials to them. HCFA can target some print materials to family members, especially materials relating to program changes. The key, however is to make the materials as visually appealing as possible, because very often there is a backlog of materials to be read. Seniors receive a lot of written materials and it is important that HCFA materials are selected to be read since often, because of time constraints, only the "most visually appealing" documents are chosen.

Because persons that are low literate have underdeveloped information processing skills, it is recommended that physicians and other providers speak in simple language and give the individual the opportunity to digest the information. It is also suggested that providers repeat instructions, and demonstrate key points visually, in combination with providing easy-to-read written materials for the patient to take home as a way to reinforce important information. Respondents noted that many providers are not aware of low literacy among their patients and overestimate levels of understanding.

Recommendations for printed materials for low literacy beneficiaries:

- Use print materials even though some individuals with the lowest literacy attainment may not be able to use them. Skill levels vary widely, so multiple versions of materials can also be helpful to address this range.
- Limited literacy individuals often have someone who assists them with literacy related tasks, so print materials can also be targeted to these individuals. However, reading levels should not be higher than eighth grade.
- The text format and the readability of the material are important factors to be taken into consideration for older adults. Contrast between text and paper, large font, short paragraphs, and simple language are all key elements to incorporate when creating print materials for elderly adults. Use bullets and relevant graphics wherever possible.
- Print materials can be formatted to include simple summary statements and graphics in the margins to accompany the text. These can be followed by the low literate senior, while the senior who reads well will most likely view the statements as an outline.

In general, seniors and others who may be low literate like easy-to-read print materials. Respondents strongly recommended that HCFA develop a reader friendly format, along with lowering the reading level generally of its print materials. Reader friendly format uses a lot of white space, illustrations of key points, large font, short paragraphs, simple sentences and bullets.

CHAPTER 5

SUMMARY

Fact. Visually impaired, hearing impaired and low literacy individuals have similar information needs about Medicare as the general beneficiary population, but generally have exaggerated gaps in information across all Medicare topics.

Implication for HCFA. The three beneficiary groups do not so much need different information on Medicare than the general population, but they need it to be **presented differently.** Low levels of literacy preclude most of these individuals from being able to read HCFA materials, such as *Your Medicare Handbook.* Accessible communication delivery methods are most important with these groups, especially targeted media (such as closed caption cable television programming or limited distribution radio formats) and interpersonal delivery through community-based organizations.

- Information should be delivered through existing social support networks, which are often well-developed within the community.
- Printed information that is used should be clear, concise, and illustrated with simple pictures wherever possible.
- Use concrete examples to illustrate abstract points. For example, an individual who has been deaf from birth has not experienced the same linguistic development and does not read at the same level as an individual with late onset hearing impairment, who has already learned the written English language.
- A wide cross section of beneficiaries would benefit from lowering the reading level of written materials and formatting them in a reader-friendly way (more white space, illustrations of key points, large font, and bullets).
- Diversify vehicles and tools for information dissemination. Examples of vehicles recommended by respondents are: (1) initial use of media to create interest in a single topic, followed by short fact sheets in which simple graphics are used to illustrate key points; (2) short video tapes with both closed caption and a sign box; and (3) regularly updated audio tapes of all written materials.

Fact. The general public is unaware of the special information needs of these groups, and that communication methods and tools can be adapted to better serve their needs.

Implication for HCFA. It is important to understand the diversity and wide range of communication abilities that characterize these populations. The general public tends to view the vision and hearing impaired as "people with

disability," and do not realize that while only a small proportion of seniors are blind or deaf, a very large proportion of seniors experience varying degrees of vision and hearing loss and are not considered "disabled." As HCFA becomes more beneficiary-centered and as the Agency develops a consistent posture with respect to people with disabilities, the approach to service provision will begin to change. Beneficiary need for services may begin to be based upon functional abilities rather than their particular eligibility category. The traditional categorical eligibility structure of public assistance programs encourages a collective perception of "the disability" rather than the perception of a person with a range of abilities. Respondents recommended that the Agency provide sensitivity training to front line customer service staff in order to raise their level of awareness that many beneficiaries may have trouble hearing, seeing, or understanding the information that is being presented.

Fact. Vision impaired, hearing impaired and low literacy beneficiaries have similar questions about Medicare but often need a great deal of health care information on services that are beyond the scope of the Medicare program.

Implication for HCFA. In order to meet the information needs of Medicare beneficiaries, and their intermediary organizations and agencies, HCFA will need to define its role within the larger health information network. There are many options for the Agency, including but not limited to: (1) providing beneficiaries with information only about the Medicare program; (2) providing information to beneficiaries about staying healthy in addition to information about the Medicare program; (3) serving as a clearinghouse for general health information; (4) serving as an information broker, referring beneficiaries to local sources; and (5) serving as a resource for comprehensive information on selected topics.

Fact. For the majority of beneficiaries in these groups, HCFA is not recognized as a primary information source on Medicare, as their vision, hearing and literacy often lead them to more local sources experienced with providing services tailored to their special needs.

Implication for HCFA. Currently, HCFA has begun to adapt its written materials to improve information access to beneficiaries with special needs, such as an audiotape version of *Your Medicare Handbook*. Because many beneficiaries in these groups are unaware of HCFA's extensive role as a value-based purchaser of health care, they do not know of these services or adapted information resources. To bridge this access gap, it is important for beneficiaries to recognize the HCFA name and associate it directly with their Medicare coverage and Medicare information. Heightening HCFA name recognition can be accomplished through a variety of ways, such as media campaigns and targeted information delivery to local community agencies

serving these groups.

Fact. Many beneficiaries in these subgroups are socially isolated and have difficulty physically accessing information. In addition, more immediate health concerns often take precedence over learning about Medicare.

Implication for HCFA. Health care is embedded among a myriad of other social services, and often beneficiaries consider these other services to be more important than Medicare (for example, for someone who is blind or visually impaired, being able to access a radio reading service or buy textbooks on tape). In many communities, well developed networks of state, local, and community organizations exist which provide an array of different services to seniors with and without disabilities. HCFA might consider providing information not only through its health care provider partners, but also through partnerships with non-healthcare oriented organizations, such as: (1) state welfare offices; (2) county and community-level social service workers (in programs such as Meals-on-Wheels, congregate meal programs, senior centers, or on-site in subsidized housing); advocacy organizations, such as Easter Seals; and private social service programs (such as those provided by the United Way).

Fact. Many members of these groups do not read above a fifth grade level.

Implication for HCFA. HCFA primarily disseminates information through print materials, which are often written above a comfortable reading level for many beneficiaries. Simple formats, lower reading levels and information provided in understandable "chunks" will increase the comprehension of these beneficiaries. It is also important to note that these three groups comprise a very large portion of the total beneficiary population. Adaptations made specifically to meet the needs of these three groups will inherently meet the needs of the larger beneficiary population.

Fact. The current beneficiary population does not often have direct access to technology, such as the Internet, faxes, and e-mail.

Implication for HCFA. The HCFA webpage, for example, is an excellent resource for Medicare information. Because this generation of beneficiaries is not as technologically inclined as future generations will be, they are unable to take advantage of this resource. Some beneficiaries are able to rely on family members or community groups to access these resources for them, however. In order to facilitate this process, HCFA may consider an intergenerational approach to information dissemination, in which materials are specifically targeted to the senior's family over the Internet.

Fact. The primary interactive communication channel between HCFA and

beneficiaries is the telephone.

Implication for HCFA. While HCFA does provide a TTY line, most hard of hearing individuals do not own or do not have easy access to a text telephone. Hearing impaired individuals (as well as the general beneficiary population) have a difficult time navigating an automated telephone menu, either because they have trouble hearing the recording or because they are confused by the numerous options listed. Respondents noted that one solution for most of the current generation of beneficiaries is to provide a live operator who is a trained customer service representative to aid the caller with his or her questions and concerns. In addition, increased awareness of hearing impairment by staff on relay services and at TTY locations will be helpful for those individuals that are hard of hearing.

In summary, over twenty-five organizations were interviewed for this Third Inventory. Inventory findings provide a concise yet detailed snapshot of the special information needs of three groups of Medicare beneficiaries who experience barriers to obtaining information, and the "best practices" organizations use to disseminate information to them. More importantly, this work is applicable across HCFA initiatives, for effective communication lies at the heart of customer-oriented service provision.